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Pathways to care for people for dementia: an international multi-centre study

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Title

Pathways to care for people for dementia: an international multi-centre study.

Running Title

Pathways to dementia care

Authors

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Abstract

Objective: the aim of the present study was to characterize the clinical pathways that people with dementia (PwD) in different countries follow to reach specialized dementia care.

Methods: we recruited 548 consecutive clinical attendees with a standardized diagnosis of dementia, in 19 specialized public centers for dementia care in 15 countries. The WHO "Encounter Form", a standardized schedule that enables data concerning basic socio-demographic, clinical and pathways data to be gathered, was completed for each participant.

Results: the median time from the appearance of the first symptoms to the first contact with specialist dementia care was 56 weeks. The primary point of access to care was the general practitioners (55.8%). Psychiatrists, geriatricians and neurologists represented the most important second point of access. In about a third of cases, PwD were prescribed psychotropic drugs (mostly antidepressants and tranquillizers). Psychosocial interventions (such as psychological counselling, psychotherapy and practical advice) were delivered in less than 3% of situations. The analyses of the 'pathways diagram' revealed that the path of PwD to receiving care is complex, diverse across countries, and that there are important barriers to clinical care.

Conclusions: the study of pathways followed by PwD to reach specialized care has implications for the subsequent course and the outcome of dementia. Insights into local differences in the clinical presentations and the implementation of currently available dementia care are essential to develop more tailored strategies for these patients, locally, nationally and internationally.

Key-words: dementia, geriatric psychiatry, pathways to care, time to diagnosis, outcome, health care policy.

Key-points:

- Pathways to care are crucial for defining tailored care policy and strategies for PwD
- Pathways to dementia care are complex and diverse across countries
- Several institutional barriers and time delays exist in dementia care yet
- Higher integration of primary and secondary care for dementia is highly needed

1. Introduction

Dementia is an umbrella term for a group of brain diseases, characterized by deterioration of cognitive and functional abilities, later associated with neurological, behavioural, affective and psychological symptoms. Due to the progressive nature of the condition, a person's ability to perform activities of daily living deteriorates over time, leading to dependence on caregivers and high levels of disability and disease burden[1-2]. Due to its high prevalence, multi-morbidity, burden of disability, and costs of care, dementia currently represents one of the most challenging global health issues[3]. Furthermore, with the current ageing rate of the population, a rise in the number of dementia cases globally is clearly expected over the upcoming decades[3-5].

One of the most challenging issues in dementia care is establishing a timely diagnosis in the course of the condition. That diagnosis is essential to shape health service configuration, to define the contents and deployment of interventions, and to enable the prompt treatment of cognitive and other symptoms as well as the planning of subsequent care, personal and health-related decision making [6-7]. While it is estimated that the incidence of dementia is now at one new case every three seconds, and that more than 46 million people worldwide live with dementia[8], the barriers to care seeking are still significant. These include poor recognition of early cognitive signs, low public awareness and misconceptions about the syndrome[9-10], all of which delay affected people and their families from seeking medical assistance and receiving dementia care[11]. Evidence suggests that nearly half of those with cognitive impairment severe enough to impact on their functional ability, do not seek help from any health care provider for at least 12 months[12-13].

Considering the high frequency of missed diagnosis in the early stages of dementia, one of the main challenges for treatment and care is developing reliable clinical pathways that enable people with memory or other cognitive problems to navigate the complex care network for dementia. Such pathways are essential for reducing the delay in time to diagnosis and for ensuring rapid access to care.

‘Pathways to care’ studies have long represented an effective and inexpensive method to characterize help-seeking behaviour of people with severe illnesses with a longitudinal course, in various fields of medicine[14-15]. The evaluation of ‘pathways to dementia care’ is particularly needed as in view of the high level of stigma and emotional distress linked to the dementia diagnosis, as well as the difficulties that people with dementia (PwD) have in getting access to appropriate health care, especially if living alone[16]. Furthermore, at a global level, healthcare systems do not adequately provide coverage of diagnostic services, and care is very often fragmented, poorly coordinated and not tailored to the needs of PwD and their families[17]. In high-income countries, care tends to be concentrated in specialist centre, with inadequate support provided by primary care. In low and middle-income countries (LMIC), services tailored for dementia may be completely lacking. For example, in Pakistan, it was recently reported that in the entire country, with a population of more than 185 million, there was only one dementia specialist[18]. A recent study[19] attempted to characterize pathways to tertiary care for PwD in an Indian region and concluded that the major points of access for dementia patients were either general practitioners or specialists in neuropsychiatry, although other people were reported to follow a ‘non-cohesive pattern’. While this study might have some interest from the perspective of dementia care in a low-middle income (LMIC) country, the small number of participants (N=35), the strictly regional focus, the qualitative approach and the use of a non-specific, semi-structured interviewing tool may limit the generalizability of those results, even for India which has wide regional variations in terms of health care and economy.

Seminal work on the pathways to mental health care was performed several years ago in collaboration with the WHO. This work confirmed the difficulties and disparities in accessing mental health care in different countries and settings, as well as making available a specific and standardized tool (the ‘encounter form’) to quickly and reliably assess the routes followed by people with mental health problems to reach specialized care[20-21]. Since then, the availability of this tool has enabled valuable comparisons among different health care systems in different countries and has demonstrated the utility of such an approach in monitoring the current needs and gaps of mental health care[22].

The aim of the present multi-centre study was to investigate, by means of a standardized and validated tool directly derived from the WHO encounter form, the pathways followed by PwD to access specialist care.

2. Methods

2.1 Participants

We examined the pathways to care of PwD who had access to one of the 19 specialist dementia care participating centers (Abeokuta, Nigeria; Bari, Italy; Basel, Switzerland; Belgrade, Serbia; Beijing, China; Hong Kong, China; Huesca, Spain; Istanbul, Turkey; Kerala, India; Nice, France; Manchester, United Kingdom; Nijmegen, The Netherlands; Rawalpindi, Pakistan; Singapore, Singapore; Seoul, South Korea; TgMures, Romania; Zaragoza, Spain; Zurich, Switzerland) between January 1st and January 31st 2017.

PwD were included in the study if they satisfied the following inclusion criteria: a) age of 65 years or older; b) no previously documented diagnosis of dementia; c) the individual had to be "newly referred" (i.e., that he or she had not sought care from any specialist dementia service within the previous 12 months) to any dementia facility (including outpatient, inpatient, emergency units); d) standardized diagnosis of dementia, according to the ICD-10 criteria[23].

No exclusion criteria were applied. All participating centres interviewed consecutive referrals who met the inclusion criteria until the target of at least 25 participants per centre was achieved.

The study protocol was originally approved by the Ethical Committee of the Coordinating Centre (University of Campania, 'L. Vanvitelli' - Naples, Italy) and then adopted by all local institutional review boards. All included participants had the capacity to provide their written informed consent to participate in the study. Prior to signing consent, all participants had been provided with a detailed description of the study aims and procedures.

2.2 Materials

We examined pathways to care of PwD in 19 specialist dementia services, using a semi-structured interview (Encounter Form) to record information about pathways to care[21]. The original version of the 'Encounter Form' was developed by the WHO and it was slightly modified to include information about carers specific for dementia settings that were not included in the original version. This latter version was approved by one of the original authors of the 'Encounter Form' (N.S.) and is available upon request.

An instruction and coding manual was supplied to each interviewer who took part in the field work at the respective study centre. The Encounter Form enabled the interviewers to record, for each enrolled patient, the following data: basic socio-demographic characteristics, main presenting neuropsychiatric problem(s), the source/type of care received prior to referral to a dementia health care professional; and, the interval from the onset of dementia-related problems to the contact with dementia health care professionals. A description of any treatment received was also recorded on the Encounter Form. The time to complete each questionnaire was 5 to 15 minutes per participant.

2.3 Analyses

The routes taken by participants seeking dementia-related health care were combined in a 'Pathway Diagram', which describes the steps needed to reach specialized dementia care, from the onset of symptoms onward. The proportion of participants taking each step of the dementia health care network is mapped onto the Pathway Diagram. Time to reach specialist and non-specialist care was compared among major pathways, different diagnostic groups, and presenting problems. We obtained mean (±standard deviation, SD) values for major variables, but when comparing time, we also provided median values, since the distribution of time intervals was significantly skewed. Categorical data were analyzed using the Chi-square test, while continuous variables were analyzed by means of the analyses of variance (ANOVA), after checking the goodness of fit for normal

distribution. All statistical analyses were performed with the SPSS software (version 19.0; SPSS Inc., Chicago, USA) and the level of significance was set at $p<0.05$ for all analyses.

3. Results

3.1 Participants

Centres recruited any consecutively referred patients during the study period of a month and there were only four individuals who refused participation among all centres. An average (±SD) of 28.4 (±6.9) participants were recruited in each centre. Thus, we recruited a total of 548 patients, the majority of whom were female (57.3%; n= 314). Their mean (±SD) age was 76.7 (±8.9) years. A simplified measure of the socio-economic status (a scale ranging from 1-“low” to 3-“high”) revealed that the majority of participants was middle class (59%; n=322), while 11% (n=62) of them belonged to the higher and 30% (n=164) to the lower socio-economic class, respectively. Slightly over half the sample was married (52.1%) or cohabitating with someone (0.2%), but almost half (i.e., 47.7%) of the enrolled participants was living alone (36.2% of them were divorced, 6.2% were single, 3.3% were widowed, 2.0% were separated). Significant differences among centres emerged for several socio-demographic characteristics: participants from India and Turkey had a lower mean age, while those from Switzerland and Hong Kong were older. As for socio-economic status, significant variations among countries were found with Hong Kong showing a greater proportion of patients in the lowest socio-economic grouping, while Switzerland and Singapore had the highest proportion of participants belonging to the highest economic class. Full details concerning basic socio-demographic data for each participating centre are provided in Table I.

<table I about here>

3.2 Problem presentation, diagnosis and dementia care pathways

In the majority of the cases (42.1%), the main problem presented at first contact with the healthcare system was related to memory issues, followed by psychiatric symptoms (20.6%; mainly major depression, 9.8%), somatic symptoms (14.7%), behavioural problems (10.1%), motor problems (4.6%). Alcohol or drug-related problems, interpersonal issues, alterations of consciousness, and settling family issues accounted only for a minority of first contacts.

The most frequent form of dementia diagnosed according to ICD-10 criteria in our sample was dementia due to Alzheimer's (61.7%; n=338), followed by vascular dementia (14.0%; n=77). Other types of dementia (e.g. fronto-temporal dementia, dementia with Lewy bodies, and Parkinson's disease dementia) accounted for 8.1% (n=45) of the sample, while "unspecified" dementia represented the 4.2% (n=23) of all cases. In 10.9% (n=59) of the cases, final diagnoses other than dementia were reported (major depressive disorder was responsible for 25.4% of those cases; n=15), while in 1.2% (n=6) of the cases no conclusive diagnosis was made; these cases were then removed from further analyses. The analysis of the distribution of dementia diagnosis per country also revealed significant differences among countries with a greater ratio of dementia due to Alzheimer's disease being diagnosed in France, Turkey and South Korea. In contrast, participants recruited in Hong Kong and Spain were more commonly diagnosed with vascular dementia compared to any other type of dementia. Further details concerning basic clinical data for each participating centre are provided in Table I.

The suggestion to first seek care for probable or possible dementia symptoms came from the symptomatic individual themselves in only in a minority of the cases (16.7%; n=92). In contrast, most often (83.3%), symptomatic individuals were asked to access dementia care by a health professional (39.0%; n=213), a relative (37.5%; n=206) or a friend (6.8%; n=37).

Only a minority of participants (6.7%; n=37) reached specialist care for dementia directly. The majority of participants arrived at specialized dementia services by accessing either primary care (55.8%; n=306) or hospital care (11.4%; n=63) first. Psychiatrists (7.6%; n=42) and neurologists

(6.5%; n=36) were seen as first healthcare providers only in a few cases (14.1%), but the importance of their role within the dementia care system increased with the length of time spent on the route of care, with psychiatrists being the most frequent second-line healthcare providers (36.9%; n=126), followed by neurologists (26.4%; n=90). Psychiatrists specialized in 'old age' or 'geriatric psychiatry', were never consulted in the first place, but became increasingly drawn in as participants progressed along the care pathway and moved into the later stages of dementia, albeit in a minority of cases (2.9%; n=4). However, it must also be pointed out that in several countries there is no such a psychiatric subspecialty and that in some settings no specific help for PwD is available at all (bearing the risk that a dementia diagnosis may lead to stigma and discrimination, rather than specialist care).

Geriatricians were rarely (1.8%; n=10) the first point of contact for people with dementia, but they managed more than one fifth (20.9%) of those first seen in primary care and more than one fourth (25.4%) of those seen in general hospital setting. Native and religious healers were first involved in the care process in 5.1% of the cases (n=27), while alternative medicine accounted for about 1% (n=6) of the first step of dementia care. Social workers and community staff supported 1.6% (n=9) of enrolled participants. The police service and legal system did not represent a significant point of access to dementia care (0,05%; n=3), but in subsequent stages of dementia care their role became more relevant such as following diagnosis and at least two healthcare providers had been consulted. The police and staff in the legal system had to manage 15.2% of people with dementia. Other professionals represented the first node of the health care pathway for dementia in 1.6% (n=9) of the cases. A simplified representation of the pathways followed by participants to reach specialist dementia care is provided in the "Pathways Diagram" (figure 1).

The contact with the first professional healthcare provider rarely resulted in an immediate and effective referral towards specialist dementia care, which occurred in only 3% of cases. About 37% of participants reached specialized dementia care by the time a second professional had been consulted, but the figure increased to 75% by the time the third professional had been consulted. In

25% of the cases, a fourth professional healthcare provider was needed for participants to reach dementia care successfully.

<Figure 1 about here>

3.3 Treatment

For most of the patients (46.5%; n=255), no treatment or management strategy was offered at the first contact with the healthcare systems. Psychotropic drugs were prescribed in the 29.9% of the cases (n=164), including mainly antidepressants (9.7%), followed by benzodiazepines or other sedatives (8.2%), antipsychotics (7.6%), anticholinergic drugs (4.0%) or mood stabilizers (<1%). Psychological counselling, psychotherapy or other psychosocial interventions were offered in only 2.7% of the cases, while practical aid or treatment for physical symptoms or comorbid physical condition accounted for 12.5% of all interventions. Religious (1.4%) and alternative (3.1%) approaches were also reported.

3.4 Delays to specialist dementia care

In the majority of the cases (76.1%), participants reached the specialist dementia care centres from within their catchment area. In all centres combined, the median total duration of time from the onset of the main problem to arrival at the dementia specialist service was 56 weeks, while the median time between first seeking care and arrival at the dementia specialist services was 48 weeks. Significant variations were observed among centres: the mean time to reach a dementia specialist centre ranged from few weeks (as for Italy and India) to years (such as in the case of Pakistan and Romania). South Korea showed the longest mean time from symptom onset to reaching the first healthcare provider (almost 2 years), while in other centres this time period was within a few weeks

(as for Singapore and Switzerland - Basel). Romania exhibited a short delay from symptom onset to the first carer (2 weeks), but a long duration (2.5 years) was needed for PwD to pass through subsequent care steps. Furthermore, participants from Nigeria and Pakistan needed more time to reach a specialist dementia centre after the first contact with their healthcare systems. A more detailed graphical account of the total duration of problems for each participating centre is provided in Figure 2.

<Figure 2 about here>

3.5 Regional data

According to the most recent classification of the World Bank (WBC) based on per capita income, participating countries were categorized as belonging to high income (France, Hong Kong, Italy, Singapore, South Korea, Switzerland, The Netherlands, United Kingdom; HIC), upper-middle income (China, Romania, Serbia, Turkey; UMIC) and lower-middle income (India, Nigeria, Pakistan; LMIC) regions. No significant differences were found as for the main access point to dementia specialist care among the WBC regions, given that in the relative majority of the cases (HIC: 62.9%; UMIC: 59.8%; LMIC: 40.8%) patients were first directed to a psychiatric unit. However, the second point of access in HIC were represented more often by a geriatric outpatient service (17.6%), while in middle income countries a geriatric hospital ward was more frequently chosen (14.7%, for UMIC; 26.8%, for LMIC).

The total duration of dementia problems before reaching specialist care, for each WBC region, is graphically represented in Figure 3.

<Figure 3 about here>

In brief, HIC showed the lowest total time from dementia symptom onset to the first contact with the health care system (25.8±52.3 weeks), followed by UMIC (43.1±68.1 weeks) and LMIC (52.9±114.9 weeks). However, UMIC had the lowest total delay in ensuring PwD to reach specialist

dementia care (67.1±75.1 weeks), with respect to both LMIC (93.5±112.3 weeks) and HIC (90.3±75.1 weeks).

4. Discussion

This is the first study to systematically investigate the pathways followed by PwD to reach specialized care in different countries, using a standardized psychometric tool. The recruited sample was large enough to provide a reliable representation of different diagnostic sub-types of dementia as well as geographic distribution and gender balance, the latter being in line with the previously reported overall female predominance among those with dementia[24]. The analysis of these pathways to care for dementia provided a detailed and previously unreported profile of a highly complex care system for dementia, with multiple help-seeking steps and significant variations among different countries and health economics (especially if compared with that of other mental disorders[25]). Several of the reported differences in dementia care may likely reflect differential characteristics of local cultures, family structure, health care service organizations, insurance policies, and health care plans among different countries. However, our results clearly highlight that complex care settings for dementia do exist in the majority of the countries which took part in the study examined and this might compel patients and their caregivers to easily find themselves "navigating in a labyrinth-like maze of services, practitioners, assessments…", especially in the first phases of dementia which are classically associated with uncertainty, confusion, anxiety, worrying about memory problems and future life[26]. In this regard, our study highlights the urgent need to define clear clinical care pathways for dementia, in order to ensure efficient sequencing for care activities, personalized clinical management of the early phases of the disease and guidance to those affected and the caregivers in the help-seeking process. Such strategies should be developed and applied to address national variations in health care systems but also to ensure equality of access to treatment and essential standards of dementia care worldwide.

The analyses of our data, grouped according to WBC, provided some relevant inputs on regional differences and similarities in dementia care. A preliminary word of caution should be spoken when evaluating these results for several reasons. First, it should be noted that our convenience sampling strategy prevented us to include countries belonging to the “lower income country” WBC category and thus further studies including countries from all WBC categories are highly needed to provide a more reliable picture of the dementia care at the world level. Further to that, the research strategy on which pathways to care studies rely clearly depend on the specific arrangements of included specialist services. Thus, it should be beard in mind that the results of the study of pathways to care is of primary use to those who work in the services which have been studied and may provide a non-exhaustive view of the global health care strategy for specific mental health issues. The greater collaboration between psychiatric and geriatric outpatient units and the shorter duration of the phase between dementia symptom onset and the first contact with the health care system observed in HIC, with respect to UMIC and LMIC, may be mostly explained in the light of the between-country variations in dementia care: while in most Western countries a specific dementia action plan has been officially approved and implemented, while in UMIC and LMIC such initiatives often represent a goal to be achieved yet. This may imply that in countries with well developed specialized services and well functioning care, the diagnosis and care processes are more efficient in the initial steps of care, while with the growing complexity of the care network, a longer time to go through multiple care steps.

Finally, the finding concerning the shortest total time needed for PwD to reach specialist dementia care in UMIC, with respect to HIC and LMIC, deserves further reflections. A tentative interpretation of this result might be related to the differences in terms of organization of primary versus secondary care levels over different countries. The lower availability of dementia specialist in LMIC might correspond on one hand to a greater availability of non-specialist carers, who might be more ready to formulate dementia diagnosis and prescribe an appropriate treatment, and, on the other hand, a relative shortage of secondary level specialist center might explain the longer time in

subsequent dementia care steps in LMIC. Another issue that should be evaluated to interpret our regional results might be related to the differences in mortality rates across countries (i.e., in poorer countries the mortality excess might influence the global rate of access health care, with some people early diagnosed with possible dementia who will never reach the specialist care). This hypothesis might well explain why a small proportion of people will get a referral to specialist in a short time (while the rest will be possibly referred to specialist care later or never), but it remains of speculative nature and it needs to be verified empirically.

Besides highlighting important regional differences, our study also provided key insights regarding the variation in clinical dementia management worldwide. In the majority of cases, general practitioners represented one of the main points of access to dementia care. This evidence is in line with previous studies on the same topic. Hinton et al[27] also reported that the "smooth pathways to diagnosis" involved primary care providers (general practitioners, nurses or other formal caregivers) who cooperated with families and patients to establish a proper diagnosis of dementia. Consistent with our findings, these authors also found that later help-seeking involved "secondary helpers" (usually specialists in neurology, psychiatry and psychology). However, this study was conducted in a defined region of the USA (Eastern Massachusetts) in a sample of only 39 family caregivers, which were further subdivided into three ethnic groups (Black, Chinese, Anglo-Europeans), thus the representativeness of such results remains limited. Another study[28] on a large sample of third generation immigrants (Italian, Chinese and Greek descendants) reported that general practitioners constituted the major resource of help for 55% of their participants, with relevant differences among different groupings based on national origin. However, this was a cross-sectional telephone survey limited to a region of Australia and it would hardly represent a more general situation.

More recently, another study from India[19] used a validated questionnaire (i.e. the Short Explanatory Model Interview) to assess pathways to care among PwD. Here, the authors also reported that a significant proportion of those affected were guided through the dementia diagnostic process by their general practitioners, although possibly after consultation with private practitioners or hospital

doctors. In contrast, our study found that the early steps in dementia care more frequently involved general practitioners and that specialists (mostly neurologists, psychiatrists and geriatricians) became involved as the care pathways progressed, assuming a more definitive role. This result is in line with previously available evidence. For example, Phillipson et al[29] reported that survey participants from general populations tended to seek help from a general practitioner either for themselves (82.2%) or for a proxy (78.7%) in the vast majority of cases. However, when general practitioners were asked about their perspectives on dementia care[30], they reported a heightened awareness of their limited skills regarding several aspects of dementia care including feeling "uncomfortable" in delivering a diagnosis of dementia. Similar studies confirmed general practitioners' reluctance to make a dementia diagnosis[11,31]. Furthermore, it has been reported that general practitioners believe that most of the care for their people with dementia should come from support services beyond primary care and that community and specialized services for dementia represent a sort of "black box" for them to which they refer patients with little knowledge of or interest in such services work[32].

This evidence should be interpreted in the light of the numerous barriers that may further hinder early detection of dementia, including reluctance of PwD to acknowledge cognitive decline, diagnosis-related stigma within families and communities, nonadherence to management plans, lack of training and confidence of primary care providers, and system-related barriers (such as lack of time during consultations and lack of support services)[33]. Our study highlights the need to properly support primary care physicians in the diagnostic process and all aspects of dementia care, with specific information regarding the concerns and barriers of the informal caregivers and those affected in the early steps of the dementia care process. Furthermore, there is a clear need to raise awareness in communities, particularly in LMIC, about dementia and the importance of seeking a diagnosis and support.

Another issue that our study pinpointed is the significant variations in dementia care among different countries. Clearly, the structure of the national health care systems may influence the

timing and the ease of access to dementia care in different countries. However, data obtained from a direct comparison of dementia care in high, middle and low-income countries with a standardized tool is missing in the current literature and our study, to the best of our knowledge, is the first to provide such evidence. Previous studies conducted in Western countries on ethnic minorities[34] highlighted that ethnic groups have culturally specific barriers to help-seeking (mainly related to disease knowledge, society and health care systems), thus, to improve access to dementia services, public health care policies should take these concerns adequately into account.

Our study has some methodological limitations, which need to be acknowledged. First, we slightly modified the classical "pathways to care" study strategy, originally developed by WHO; however, this allowed to better capture the circumstances relevant to dementia and to ensure a good compromise between feasibility, efforts and representativeness of obtained results; furthermore, having included more participants (than the mandatory 25 cases per each center) and having allowed a longer observation time (instead of a single working month) may provide an even more detailed account of dementia care. Unfortunately, our sample was not stratified for any variable and the countries involved in the study were selected on a convenience base rather than on a random or other more specific criterion; of course, addressing these issues in future studies may enhance the quality of the data on dementia care worldwide. Our study also did not explore cultural aspects of dementia and thus we could not make inferences about the regional differences among centres; however, given the importance that differences in social and cultural characteristics of care settings may have with respect to contents and delivery of dementia care, the relationship between dementia care and the general attitude towards elderly should constitute a focus for further studies.

Our study provided a retrospective account of pathways taken by PwD and this implies that no data are available for patients who dropped out after the initial consultations. Indeed, the "fragmented"[19] or "non-cohesive"[27] pathway may be less accurately captured by this study approach. Finally, our survey did not include any measure of satisfaction of care throughout the entire pathway for dementia patients and their caregivers, while a more exhaustive evaluation of the dementia care

process should include this aspect. Thus, further studies with larger samples, with a more specific selection of country/center involved and with longitudinal experimental designs are still needed.

5. Conclusions

In spite of the above limitations, our international study demonstrated that the characterization of pathways to dementia care represents a valuable approach to provide a low-cost, easily accessible and yet reliable account of this care process. It has also highlighted that the complex needs of people with dementia are far from being satisfactorily met under routine care conditions worldwide. New and specific strategies aimed to increase awareness about dementia among general practitioners and in the general population will have to be implemented in the future, at a global level.

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Data Sharing

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Table I. Basic clinical and socio-demographic data

Table I. Basic clinical and socio-demographic data

Centre	Bari	Basel	Beijing	Belgrade CMD	Belgrade IMH	Hong Kong	Huesca	Abeokuta	Istanbul	Kerala	Manchester	Nice	Nijmegen	Rawalpindi	Seoul	Singapore	Tg Mures
Country	**Italy**	**Switzerland**	**China**	**Serbia**	**Serbia**	**China**	**Spain**	**Nigeria**	**Turkey**	**India**	**UK**	**France**	**Netherlands**	**Pakistan**	**South Korea**	**Singapore**	**Romania**
N	26	31	25	28	27	53	28	25	32	23	23	28	39	25	30	30	25
Age* (years; mean±SD)	77.3±8.7	81.0±8.7	78.6±7.1	76.3±9.4	75.8±10.4	79.9±7.5	78.1±8.9	74.4±9.2	73.8±8.0	73.8±6.9	77.7±8.1	76.7±7.3	76.1±10.2	67.6±8.2	73.8±9.1	74.9±8.6	77.9±8.4
Sex (male %)	46,1%	35,5%	30,8%	40,7%	25,0%	34,0%	42,9%	52,0%	37,5%	47,8%	39,1%	50,0%	64,1%	44,0%	33,3%	63,3%	40,0%
MS (%)																	
Single	0,0%	32,3%	0,0%	7,1%	11,1%	3,8%	7,1%	0,0%	3,1%	0,0%	4,3%	10,7%	7,7%	4,0%	6,7%	6,7%	0,0%
Married	53,8%	45,2%	56,0%	39,3%	33,3%	45,3%	50,0%	44,0%	59,4%	52,2%	73,9%	57,1%	48,7%	64,0%	50,0%	70,0%	68,0%
Separated	3,8%	0,0%	8,0%	0,0%	0,0%	5,7%	0,0%	8,0%	0,0%	0,0%	4,3%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%
Divorced	3,8%	3,2%	0,0%	3,6%	0,0%	5,7%	3,6%	0,0%	3,1%	0,0%	0,0%	3,6%	12,8%	0,0%	3,3%	3,3%	0,0%
Widowed	38,5%	12,9%	36,0%	50,0%	55,6%	39,6%	39,3%	48,0%	34,4%	47,8%	17,4%	28,6%	30,8%	32,0%	40,0%	16,7%	32,0%
Cohabitating	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	3,3%	0,0%
SES (%)*																	
High	11,5%	3,2%	20,0%	10,7%	11,1%	5,7%	0,0%	8,0%	9,4%	8,7%	8,7%	17,9%	23,1%	8,0%	10,0%	33,3%	4,0%
Average	61,5%	80,6%	68,0%	42,9%	44,4%	22,6%	96,4%	60,0%	59,4%	52,2%	78,3%	53,6%	71,8%	56,0%	56,7%	66,7%	80,0%
Low	26,9%	16,1%	12,0%	46,4%	44,4%	71,7%	3,6%	32,0%	31,3%	39,1%	13,0%	28,6%	5,1%	36,0%	33,3%	0,0%	16,0%
ICD-10 Diagnosis*																	
AD (%)	57,7%	61,3%	68,0%	46,4%	48,1%	35,8%	78,6%	40,0%	87,5%	65,2%	47,8%	96,4%	38,5%	80,0%	86,7%	16,7%	68,0%
VD (%)	23,1%	0,0%	4,0%	14,3%	44,4%	37,7%	7,1%	36,0%	0,0%	30,4%	17,4%	3,6%	12,8%	0,0%	3,3%	10,0%	20,0%
OD (%)	19,2%	38,7%	28,0%	39,3%	7,4%	26,4%	14,3%	24,0%	12,5%	4,3%	34,8%	0,0%	48,7%	20,0%	10,0%	73,3%	12,0%

Belgrade CMD= Clinic for Mental Disorders; Belgrade IMH= Institute of Mental Health; Clinic for Mental Disorders;SES=socio-economic status; MS=marital status; AD= Alzheimer's Disease; VD= Vascular Dementia; OD= other dementia type. *p<0.001; statistically significant difference among centres for the corresponding variable (ANOVA or Chi square tests were used as appropriate).

Figure 1. The “pathways diagram” for dementia care.

Figure 1 here

The diagram represents a simplified account of the routes taken by patients with dementia to reach specialized dementia care (i.e., “memory clinic”). The thickness of each arrow represents graphically the proportion of patients taking each route. Most patients were seen in primary care settings and then redirected to neurological and geriatric settings (including both outpatient and inpatient units), while psychiatric (including old age psychiatric) settings were more involved at later stages of the dementia care pathway. Patients reached memory clinics through direct access in less than 10% of the cases. When patients were seen in a general hospital first, they were directly sent to a memory clinic in the majority of the cases although some of them required a further specialist consultation (in geriatric, psychiatric and neurology settings). All “other settings” (including home care settings, alternative medicine settings, native or religious medicine settings, social services, legal system) accounted for a minority of patients only.

Figure 2. Delays in reaching specialist ED care, per country.

Figure 2 here

Mean values of time (days) needed from dementia symptom onset to first seeking care (in black) and from first carer to the “memory clinic” (in grey) are shown for the total sample (top) and for each centre. Belgrade CMD= Clinic for Mental Disorders; Belgrade IMH= Institute of Mental Health.

Figure 3. Delays in reaching specialist ED care, per WBC groups.

Figure 3 here

Mean values of time (weeks) needed from dementia symptom onset to first seeking care (in black) and from first carer to the "memory clinic" (in grey) are shown for high income countries (top), upper-middle income countries (middle) and lower-middle income countries (bottom). WBC: World bank classification.